

INDEPENDENTLY

NEWSLETTER

June 2009



Phil Hope, Minister for Social Care, takes questions from delegates at the wave 2 user-led organisations conference organised by the Department of Health and chaired by NCIL's Director Sue Bott

The newsletter from NCIL for disabled people about Independent Living, Direct Payments, Individual Budgets, Personal Assistance & more...

Also available in large print, Braille, audio tape, PC floppy disc, email and on Website

NCIL
National Centre for Independent Living

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A WORD FROM THE CHAIR

NCIL is on a roll. After a long trawl we finally moved to new premises in early March. They are smart, accessible, trendy, and what's more we are even paying less rent than we did before!

But more importantly, we have now secured new three-year funding from the Department of Health for our core activities. Our two funding bids cover:



**Mike
Smith**

Department of Health section 64 User-led Organisations Network

This project is to further the development and sustainability of ULOs and will include holding a register of ULOs, sharing of best practice, information and learning using our website, and holding regional networking events.

Department of Health section 64 Strategic Partnership (with RADAR and Shaping Our Lives)

The aim of the partnership is to facilitate partnership working between DH and disabled people's organisations.

Care Quality Commission Experts by Experience

This project will be much as it was last year except there will be more of an emphasis on service inspections rather than domiciliary care.

This will mean changes in the way that we manage our organisation and we are currently under a review of what staff we need to fulfil these new and exciting opportunities. Have a look on the Guardian website or our own website the details if you're looking for a new job!

From my perspective these new funding bids also give us an exciting opportunity to better help develop and build the relationship between you, our members, as user led organisations. At last year's conference we talked about the challenges local Centres for Independent Living face, and we hope that the learning and sharing that arises from these programmes

will be of significant benefit to you all.

We are also planning on launching our new policy forum shortly. This will be a virtual network of our full members that will allow us to share developments we are involved in at a national level, together with providing a network view to disseminate local best practice and experience. Watch out for an e-mail soon launching this, and please do respond.

Even with our new funding streams, resources are tight, and we are looking carefully at how we provide certain services, including our information service. Our new staffing structure should deliver more two-way communication between us and our members, but it may mean that we have to restrict the hours that our information service is available each day.

In line with many organisations operating in the charity and not-for-profit sectors, we are looking at other ways to get more outputs from the limited resources that we have. We are already working with Shaping Our Lives and RADAR as part of our joint strategic funding from the Department of Health. We are also exploring ways to work alongside other organisations such as Disability Alliance who have an interest in independent living and complement what we do. Without losing our unique value, we are keen to ensure that we work in collaborative ways to ensure that we achieve our overall objectives.

I have been quite busy on behalf of NCIL. I spoke at the all-party Parliamentary group on social care recently, specifically talking about the relevance of user led organisations to the personalisation and transformation of social care programme. There has never been a better climate in policy terms to get the message across about the value of user led organ-

isations, advocacy and peer support. NCIL has recently completed a review of personalisation and peer support which is available on our website or by contacting our office.

Finally we have been celebrating the 50th birthday of our founder and stalwart of the independent living movement Baroness Jane Campbell who has received her greatest award yet – a crippen cartoon. Go Jane go!



Healthcare Direct Payments and continuing care – a legal decision and a Government Bill

The bad news first; an important legal decision is likely to have an effect on many people using direct payments with NHS support. The March 2009 Harrison judgement has ruled that it is illegal for the NHS to contribute to direct payments.

This case was taken by two disabled people needing personal assistants. The Primary Care Trusts (PCT) involved had previously contributed NHS funds to local authorities to provide direct payments which gave significant control and independence to the disabled people.

However, Department of Health (DOH) guidance questioned the legitimacy of this kind of arrangement. The guidance has meant the PCTs will commission agencies to provide PAs rather than contribute towards direct payments. This is a more bureaucratic and expensive system.

But strictly following NHS guidance means PCTs contributing to direct payments is no longer possible. The judgement ruled that:

“NHS services cannot be provided as part of an Individual Budget or through Direct Payments, and Our Health, Our Care, Our Say: A New Direction for Community Services makes it clear that these will not be extended to NHS healthcare in the near future. This means that when an individual begins to receive NHS Continuing Healthcare they may experience a loss of control over their care which they had previously exercised through Direct Payments or similar.”

However the slightly good news is that, contrary to the 2005 ‘Our Health, Our Care, Our Say’ white paper, the Government is progressing a Health Bill through parliament which will allow NHS funds to be used in health direct payments.

NCIL co-founder and Trustee, Baroness Jane Campbell, has been seeking amendments to the Bill to ensure people are able to receive support from user-led organisations to use health direct payments. The Bill will allow pilots of healthcare direct payments in some areas. NCIL has been invited to join the Department of Health's 'Direct Payments in Health Project Board'. In the longer-term NCIL hopes PCTs and local authorities will jointly provide direct payments across the country. But in the short-term

the Harrison ruling will sadly mean most PCTs examine their procedures and reduce disabled people's control over healthcare services.



For further information on the Health Bill or a copy of the legal decision please contact Neil Coyle at policy@ncil.org.uk

RIGHT TO CONTROL WHAT IS IT?

The power for disabled people to make informed decisions about how to use the money available for support is contained in part 2 of the welfare reform bill currently going through Parliament. It has passed all its commons stages and is now in the House of Lords. The Bill provides for regulation that will:

- Require authorities to tell disabled people how much money is available
- Require authorities to plan with disabled people how best to use the money to meet support needs
- Enable disabled people to choose the degree of control over the money for support they receive by having a direct payment, allowing the authority to organise support or a mixture of the two.



The right to control will not be rolled out everywhere as soon as the legislation becomes law. Instead from next year there will be a number, of what the government are calling, trailblazer sites. These are apparently different from pilot sites in that they will not be testing out whether right to control is a good idea or not but testing out how it is to be done.

On June 11th a consultation is to be launched into how the trailblazers should be designed and what funding streams should be included. This will include funding provided by the Department for Work and Pensions(DWP) such as Access to Work and the Independent Living fund. Social care and the Disabled Facilities Grant will also be considered. An advisory group has been established to look at how the right to control can be implemented. NCIL are members of this group.

You can be forgiven for thinking this all sounds rather confusing. We have local authorities introducing personal budgets for social care through the Putting People First programme for which there is no provision in legislation, we have the introduction of personal health budgets in a number of pilot areas provided for in the Health Bill currently going through Parliament and we have the power to regulate to introduce right to control initially in a small number of trailblazer sites in the Welfare Reform Bill. If only the government would just support Lord Ashley's Independent Living Bill, our right to control and how all our support needs are met could be solved in one go!

SOCIAL CARE TRANSFORMATION MONEY

Social Care Transformation money – How is it being spent by your local authority?

The government programme to transform social care 'Putting People First' was launched in a blaze of glory in December 2007. The idea is that by 2011 everyone who has social care support at home will have an individual budget. To implement this programme the department of Health made £520 million available to local authorities spread over three years finishing in March 2011.

It will come as no big surprise to learn that, according to data put together by the Association of Directors of Adult Social Care and the Local Government Association, so far local authorities have spent this additional funding on internal staffing costs such as setting up transformation teams. Hardly any money has gone anywhere else and certainly not to user led organisations who are needed to support people in planning and using their individual budget.



There are some honourable exceptions. For example Northamptonshire County Council is funding Disabled People's Alliance Northamptonshire to run a citizen leaders programme to help people who manage their own support or who do so on behalf of a family member. Essex County Council have seconded a senior manager to Essex Coalition of Disabled People (ECDP) for 12 months with the aim of providing ECDP with support to accelerate its provision of support planning and brokerage services to all disabled people.

The Department of Health has recently issued new guidance to local ►

- ▶ authorities to clarify the direction in which it intends local authorities should be moving with the reform of social care and how the transformation money should be spent. This guidance can be found on the DH website www.dh.gov.uk go to publications and look under local authority guidance. The reference is LAC (DH) (2009) 1. It makes interesting reading for our organisations.

The guidance makes clear that disabled people and our organisations should be involved in the design, commissioning and evaluation of services (para 14 iii). Furthermore it states that there should be 'An enabling framework to ensure people can exercise choice and control with accessible advocacy, peer support and brokerage systems with strong links to user led organisations.' (para 15 bullet point 6)

Finally the guidance challenges local authorities who may be tempted to spend the transformation money on their own current priorities and not on transforming social care. 'Failure to use the resources available to drive this transformation is not acceptable and the grant monies may have to be paid back if this happens'. (para 49)

The relationship between national and local government is not an easy one. On the one hand national government is reluctant to dictate what local government should do but on the other hand it is not easy for local government to totally ignore national intentions. So if you are not already doing, use this guidance to challenge your local authority.

User Led Organisations – The latest from the department of Health ULO project

At a conference on 19th march the wave 2 action and learning sites funded by the department of Health ULO development fund were announced. The 13 sites are:

West of England Centre for Independent Living
Southampton Centre for Independent living
Disability Action Islington
Disability Cornwall
Leicester Centre for Integrated Living
Derbyshire Coalition for Inclusive Living
DOTS Disability Community Interest Company
Newham People First
Herefordshire Centre for Independent Living
Disability Croydon
Disability Resource Centre
Disability Solutions
DIAL Doncaster

The learning from the wave 1 action and learning sites will be posted up on NCIL's website at the end of July.

There will be no wave 3 funding. Instead £75,000 per region has been made available to Deputy Regional Directors to support capacity building of ULOs. Deputy Regional Directors are based at the nine regional government offices in England and are responsible for developing social care in their region. There will be an opportunity for regions to bid for further funding in the autumn. Three regions have received an additional £33,000 each as they were poorly represented in applications for the wave 2 sites. They are Eastern, North West and South East.

The Office for Disability Issues has also provided a further £100,000 per region for ULO capacity building. This is partly to ensure that recommendation 4.3 in Improving the Life Chances of disabled People for a ULO in every ►

- ▶ locality by 2010 is realised but also in recognition of the importance disabled people's organisations will play in providing support and advice to people in implementing the right to control trailblazers. (see separate article on the right to control). So the advice is find out who your regional deputy director is and start asking them what they are doing to support ULOs.



Phil Hope, Minister for Social Care, and NCIL's Director Sue Bott

The baseline research to establish an idea of how many ULOs there are in England is nearing completion and should be published soon. Thank you to all those who took the time to fill in the questionnaire.

The Department of Health have produced a booklet containing information for local authorities called '*Working together with user led organisations*'. Amongst others it has been endorsed by the Local Government Association and the Association of Directors of Adult Social Services. It is a useful tool to use in raising points with your local authority. You can find it at www.dh.gov.uk/publications.

Please let NCIL know what is happening in your area. If it is good news then we can let other people know your example of good practice. If it is not so good, or nothing is happening at all, we might be able to help get things moving.

EU HANDBOOK ON PROMOTING DISABILITY EQUALITY

The Disability Discrimination Act (2005) placed a duty on the public sector to promote disability equality. To examine 'what works' the European Union is funding RADAR to produce a handbook for public sector bodies on how to promote disability equality.



To help more public bodies develop good disability equality schemes and be able to effectively promote equality, RADAR are looking for examples of good work from across the public sector to illustrate the handbook.

RADAR are looking for effective examples where:

- Involving disabled people was beneficial to the public organisation's performance or culture, either directly or indirectly.
- Gathering evidence highlighted something surprising which the public body was then able to address.
- Actions within a Disability Equality Scheme led to practical outcomes for disabled people
- Effective equality impact assessments has made a difference to the implementation of a policy, the running of a service or the design of an initiative.

It is important that we try and encourage and support public bodies to better promote equality. It would be helpful if you could consider whether there are any examples you can think of; or if you could encourage public organisations you work with who might have good examples to contribute.

RADAR are not expecting examples to have necessarily changed the world, but hope you will have some examples which have made a practical difference. Examples can be made anonymous if you would prefer.

If you have examples then please send them to Marie Pye at: marie.pye@ntlworld.com

ADULT CARE AND SUPPORT REFORM GREEN PAPER DUE IMMINENTLY



The Government committed in the April Budget to publish the Adult Care and Support Reform Green Paper in June 2009. It will reveal proposals for the future of adult care and support services in England.

The green paper will cover social services but will also include some benefits and

other support mechanisms. It follows a 'national debate' on care reform. NCIL and many members contributed to the debate, which closed in November 2008. The green paper should include consideration of many of the issues raised during the national debate.

NCIL is hopeful that equality and human rights, and a national entitlement will figure prominently. However we are fearful that, in the current economic climate, the Government options might be very limited and may include passing benefits like Attendance Allowance (and possibly other national benefits) to local authorities to distribute. We remain convinced that the needs of disabled people and the Government vision for reform will not be met without significant investment.

NCIL will be responding to the green paper and welcomes your input. Contact Neil Coyle at policy@ncil.org.uk for further information.

In February 2009 an important legal case was heard at the High Court concerning care service charges and the assessment of disability related expenditure (DRE). In 'B v Cornwall County Council' the decision was that Cornwall had not assessed DRE properly. The decision potentially leaves many local authorities open to challenge.

NCIL led some research and published a report on charges and DRE in 2008 ('Charging into Poverty?') for the Coalition on Charging. We do not believe that most local authorities meet their obligations to assess DRE or record the impact of charges properly.



The judge (Justice Hickinbottom) chose to highlight the requirements for engagement between local authorities, 'service users' and any carers:

'The Community Care Assessment Directions 2004 and the 2003 Guidance require that an authority engages with, and tries to agree with a service user and his carers, both the steps that the authority will take in relation to identified eligible needs and also in the assessment of charging.'

The case strongly stressed the need for charges to be agreed with people needing support (and their families as appropriate). This is not always the case, with some local authorities imposing charges on families with little negotiation or transparency. The judge ruled that Cornwall had acted ►

- ▶ unlawfully in failing to engage. If you do not have your DRE assessed fairly and fully you may be able to challenge your local authority using the Cornwall decision as a precedent.

The judge also emphasised the statutory guidance that local authorities should:

"allow for reasonable expenditure needed for independent living by the disabled person. Items where the user has little or no choice other than to incur the expenditure, in order to maintain independence of life, should normally be allowed."

The judge ruled that, contrary to Cornwall policy, holidays can – and should – be considered DRE. The decision also backed payments to family members ('homestay costs') to support independent living. This may be good news for some disabled people and their families living in local authorities with restrictive parameters on what can be claimed as essential expenditure.

For a copy of the 'B v Cornwall County Council' legal decision, the 'Charging into Poverty?' report or for further information please contact Neil Coyle at policy@ncil.org.uk

The National Centre for Independent Living Experts by Experience

Since 2006 NCIL have been working with the Commission for Social Care Inspection (CSCI) on the Experts by Experience project. The new Care Quality Commission (CQC) is now in place, and NCIL is pleased to let our members know CQC have extended our contract for a further year. The Experts by Experience project is a well respect and valued by the new Commission and hopefully will build on the previous work undertaken by CSCI.

NCIL continues to work alongside other voluntary organisations on the Experts by Experience Project, and the full list can be found on CQC's website www.cqc.org.uk As in previous years,



NCIL are working in partnership with other user led organisations to ensure that experts are supported locally. Unfortunately, Herefordshire Centre for Independent Living are not able to continue to support the project and NCIL would like to say a big thank you for their previous contributions.

CSCI worked with seven regions across the country, however the new Commission has reverted to working in nine regions across England.

NCIL have been contracted to provide Experts by Experience for a minimum of 338 Inspections across different service user groups, including mental health, physical and sensory impairment and learning disability. These inspections will take place in residential care homes and for domiciliary care agencies. NCIL are also providing Experts by Experience when requested for Adult Social Service Inspections. NCIL and our member user led organisations have approximately 60 Experts across the country

NCIL member user led organisations working with us on the project are: ►

- ▶ • Southampton CIL are covering the South East region
- Bristol & South Gloucestershire People First are covering the
- South West region
- Essex Coalition of Disabled People are covering the Eastern region
- Derbyshire Coalition of Inclusive Living are covering the
- East Midlands region
- Cheshire Centre for Independent Living are covering the
- North West region
- Choices & Rights Disability Coalition are covering the Yorkshire & Humberside region
- Darlington Association on Disability are covering the North East region

NCIL are covering London/South West/West Midlands

At NCIL, all our Experts are disabled people, Experts by Experience have a wide range of experience, particularly in using social care services. Experts support Inspectors, by talking to and sharing experiences with people who use the services being inspected. Experts then write a short report and this is included in the Inspector's report and is then made available to the general public on the website.

Watch out for news of this year's freedom drive in Strasbourg in September when the European Network on Independent Living will be 20years old. Contact Robert Droy at Southampton CIL for more details.

You can get involved and support NCIL by:

Making a donation

Sponsoring one of our activities

Taking part in one of our campaigns

Contributing to our newsletter

Joining as a member

Using our training services

Contact us

Information: info@ncil.org.uk

Campaigning: policy@ncil.org.uk

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Finance: finance@ncil.org.uk

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Independent living insurance policy

At Fish, we offer two levels of cover for those taking advantage of direct payments (Independent living) to choose and control their own support, or fund their support/care privately, so they can enjoy independent living. Whilst direct payments provide welcome freedom and choice, they also bring responsibilities and potential liabilities as personal and care assistants are directly employed. You must by law, whether you receive direct payments or employ someone using your own funds, have employer's liability insurance.

Such obligations may have in the past put off some disabled & older people from benefitting from direct payments and enjoying greater control of their lives. Our full cover policy is designed to ease such concerns by providing not just extended insurance cover but access to a 24-hour employment law advice line to help you prevent or professionally manage any disputes. Staffed by qualified employment law advisors this will give you immediate access to advice on issues such as disciplinary matters, dismissal, absenteeism, health and safety regulations, change of duties and harassment. In addition, should an employment dispute reach court or tribunal, the policy will cover legal costs to resist and defend a case and awards which may be made against you for unfair dismissal or discrimination.

If you do not have experience as an employer we strongly recommend you take our full cover insurance. You may also want to contact your local direct payment support service.

The table opposite provides a simple comparison between the two levels of cover:

	Basic Cover	Full Cover
Section 1		
Employer's Liability	Limit £20 million	Limit £20 million
Indemnity to Principal	✓	✓
Public Liability	✓	✓
Section 2		
Personal Accident	x	✓
Personal Accident of Employee	x	✓
Errors and Omissions by Employee	x	✓
Additional Expenses	x	✓
Infidelity of Employee	x	✓
Employment Tribunal Costs	x	✓
Indemnity to Others	x	✓
Section 3		
Employment Tribunal Legal Defence Fees	x	✓
Employment Tribunal Awards and Compensation	x	✓
24 Hour Employment Law Advice Line	x	✓
Access to Web Service	x	✓
Premium	£76.65*	£134.40*

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INSURING YOUR INDEPENDENCE



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